



Transforming Communities for Inclusion – Asia

**Convenor (2014- ): Bapu Trust for Research on Mind & Discourse  
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**Submission to the UNCRPD Monitoring Committee, Day of General Discussion, Article 19**

### **Executive Summary**

TCI Asia is an Asian alliance of persons with psychosocial disabilities and their supporters, which exists *to enhance the pedagogy and practice of Article 19 for the region*. We are delighted to participate in DGD proceedings towards a General Comment on Article 19, based on wisdom gained from several country visits, dialoguing with stakeholders and 4 annual plenary consultative processes established since 2012 in the Asian region. Our submission (1) makes a strong appeal to the Committee to elaborate and provide a rich picture of the meaning of ‘communities’ and ‘inclusive’ communities. (2) Inclusive communities are a reflection of the human aspiration to love, care and share, as contemporary social and economic theories show. (3) A number of good practice examples exist, to explicate 19(2) of the CRPD, cited herein. (4) Enabling laws per country would protect the right to live independently and be included in communities as a legally recognized human right.

### **About TCI Asia**

**TCI Asia** (*Transforming communities for Inclusion of persons with psychosocial disabilities, Asia*) is an Asian Alliance of people with psychosocial disabilities, and cross disability supporters, focussing on Article 19 and its realization in the Asian region. Since 2012, TCI Asia has made several country visits, 4 annual plenary consultative processes, 1 strategy development workshop, and has engaged upto 15 member countries, to enhance the pedagogy and practice of Article 19 for the region<sup>1</sup>. We are delighted that the Monitoring Committee of the Convention on the Rights of persons with Disabilities (CRPD) is holding a Day of General Discussion, towards a General Comment on Article 19.

### **General provisions of Article 19**

Other than being a human right, Article 19 is also the overall purpose of realizing the CRPD: All persons with disabilities will live in the community and be included to live independently and to participate on an equal basis with others. Article 19 may be rightly considered to be the heart of the convention, even though it is not a new or a higher human right. The three key elements of article 19 are choice, support and inclusion. The four key stakeholders States must address in implementing article 19 are persons with disabilities, their families; service providers both disability specific services and the mainstream services and the community at large. The *comprehensiveness* of Article 19 invites an inclusive world for *everybody*, not just persons with disabilities. The General Assembly interventions at the time of HLMDD and the making of the SDGs suggest that policy must move

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<sup>1</sup> This submission draws from the consultative processes done between 2012-2015 of TCI Asia. We are grateful to all member participants, allies, partners, stakeholders and sponsors for the support and contribution.

access to Development from welfarism to a framework of inclusion, choice and human rights<sup>2</sup>. Article 19 General Comment is a likely site for articulating this idea.

Article 19 makes reference to “*Community*” [7] times. We urge the Committee to elaborate on interpretation of ‘Community’, and provide a rich picture of how an ‘Inclusive community’ would look. The Thematic study by the OHCHR on Article 19 has exemplified in detail, *what does not constitute community*. The study has helped us to challenge the colonial view about persons with psychosocial disabilities. We urge the Committee to consider the Thematic Study as making a significant contribution to guiding states parties in removing the traditional barriers for realizing Article 19<sup>3</sup>, viz. institutionalization. It is however important to also layout the full and robust scope of *what is community*, in a modern human rights compliant society, in explicating Article 19.

In a meeting in Pune (May, 2013) TCI Asia members advocated that personal identity cannot be reduced to being just a user of a medical service, as often happens in communities. Identity encompasses having opportunities in taking on multiple roles, such as parent, sibling, spouse, teacher, banker, pastor, farmer, postman, neighbour etc. and to be able to contribute emotionally and positively to the welfare of the society where we live. There are many cultures of the world where caring for others, emotional connection and altruism continues to prevail as a basic human duty or even a personal aspiration for living a ‘happy’ and ‘purposeful’ life in the company of other human beings, and the essence of *community*. Article 19 could be interpreted as a reflection of this aspiration. Extensive studies in neurodiversity and on ‘happiness’ are evidence that empathy is essentially human<sup>4</sup>.

*Community* is proposed to stand for the availability of ‘social capital’<sup>5</sup> and ‘local actor networks’<sup>6</sup>, a collection of individuals, groups, families, neighbourhoods in local environments who come together, sometimes to reach a reasoned out functional objective together, or sometimes to connect on human basis for sharing and caring for each other without any necessary preconditions or proposed outcomes. Such networks bind families, individuals, cattle, plant life, other life forms, inanimate objects, land, water, food, and other actions and artefacts of human social living into an organic whole, embodying a vision for a sustainable world contained within extant Development frameworks such as the SDGs. We appeal that, the Committee recognize the importance of *transforming communities so that they become emotionally sustainable, to facilitate the inclusion of everybody, and for the preservation of a peaceful and caring planet*.

New social and economic theories provides a number of concepts to capture this shift in thinking about community, from the point of view of local networks, self determinism of peoples and sustainability of human habitats, especially cities. For example, in the ‘capability’ approach<sup>7</sup>, an economic theory based on the theory of Justice, there is a need to evaluate policy and program outcomes based on the equability in the range of opportunities a person has, to achieve a certain desired state of being. In this approach, two aspects are important to address (1) recognizing agency of all persons with disabilities and (2) creation of choice by improving community inclusion. We appeal to the Committee to explicate Article 19 by considering newer conceptualization of *community*, within the context of Development.

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<sup>2</sup> WNUSP and Bapu Trust, (2013). “Human Rights of persons with psychosocial disabilities in the post 2015 Inclusive Development Agenda: Towards HLMDD, September 2013”.

<sup>3</sup> OHCHR (2014) “Thematic study on the right of persons with disabilities to live independently and be included in the community” A/HRC/28/37 12<sup>th</sup> December 2014.

<sup>4</sup> Matthieu Ricard, (2003) *Happiness. A Guide to Developing life’s most important skill*. Little, Brown and Company, New York.

<sup>5</sup> McKenzie, K. “Globalisation, Social Capital and Mental Health”, in *Global Social Policy*, 2008, Vol. 8, pp. 359-377.

<sup>6</sup> A concept developed by Latour, Bruno in his book, (2010) *The making of law: An ethnography of the conseil d’etat*. Cambridge: Polity Press.

<sup>7</sup> Sen, A. K. (2009). *The idea of justice*. London: Penguin, Allen Lane.

## Specific provisions of Article 19

In the Asian region, even though mental health legislations do not exist in many countries, and some have recently adopted new coercive mental health laws, mental institutions are coming up quite fast and in numbers, resulting in the escalation of barriers to inclusion in communities<sup>8 9 10</sup>. This trend to associate modernisation with imposing buildings and infrastructure, and closed door facilities as compulsory places of residence, has elicited strong Concluding Observations from the CRPD Committee in the Asian context, for example, in the case of China and Korea, both of which have fairly recent mental health laws and an outsized number of mental institutions.

We propose that, the General Comment on Article 19 must restrain this worrying trend emerging in Asia, by

(1) giving specific guidance to state parties to enact new laws and also revision of constitutional jurisprudence by unconditionally protecting the right to live independently and to be included in communities.

(2) enlisting illustrative actions and programs that need to be taken by state parties to capacity build and transform families and communities for inclusion and for independent living.

We appeal to the Committee that cultural contexts may determine choice of residential facilities and services, and as the Thematic study has noted, “the right covered under the article (19) was not limited to the provision of services available in developed countries”. Comprehensive enlistment of illustrative examples can be cited in the General Comment, which will explicate the diversity of services that need to exist, to fully embody the Article 19(b) provision of *choice*.

A number of western ‘alternatives’ in community, neighbourhood and family development can be illustratively enlisted, such as *Soteria house*, *Open Dialogue*<sup>11 12</sup>, etc. which may be applied universally. In high income countries of Asia, there are existing self managed models that can be adapted such as the ClubHouse, Independent Living or Hostel models, which are preferred by persons with psychosocial disabilities<sup>13</sup>. Personal assistance would include simpler acts of companionship and offer psychosocial support, actions that come within the rubric of ‘*Being with*’ or ‘*being present to*’ someone (with a psychosocial disability). There is a very audible advocacy globally, and in Asia, for *peer support* and *community based care giving systems*, based on the values and principles of the CRPD.

Asian low income country examples also exist of ‘good practices’ when a person is in crisis and is at higher risk for being institutionalized. A program provides peer support, night shelters and other essential services on the streets<sup>14</sup> with the support of the local authorities. Another program, also with the co-operation of local authorities, provides a ‘circle of care’ establishing a ‘neighbourhood

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<sup>8</sup> TCI Asia, Working Group on Strategy Development Meeting, APCD Training Center, Bangkok, 9-11 June, 2015

<sup>9</sup> KAMI, (2013). Parallel report on the situation of persons with mental illness in Korea. Submission to the UNCRPD Committee.

<sup>10</sup> Mr. WonYong Kim, NHRC investigator, Korea, who presented the Parallel report before the CRPD committee, noted the higher occurrence of mental institutions in Korea, following adoption of a new mental health law. In Korea, 73.5% cases are involuntary, 4 times as high as other countries. 262 days average stay.

<sup>11</sup> Finland, <https://www.youtube.com/watch?v=aBjlvnRFja4>

<sup>12</sup> Peter Statsny and Peter Lehmann, [Eds.] (2007). *Alternatives beyond psychiatry*. Peter Lehmann Publishing, Berlin.

<sup>13</sup> TCI Asia, (2014). 2<sup>nd</sup> Plenary, Hotel Prince Palace, Bangkok.

<sup>14</sup> Ishwar Sankalp, Kolkatta, India.

alert' system to be with persons who may be in need of crisis support<sup>15</sup>, involving a diversity of trained non-formal care givers, community members, and family members. When there is conflict over the question of forced care, a community negotiation and capacity building module is initiated by the service provider, so that families feel empowered to give love, care and support. In such programs, closer to home, social networks and neighbourhood, the person is not removed from the community, rather the community is reminded of their aspiration to give love and care in compassionate ways. The families are also taught to provide reasonable accommodation and restore dignity of the person at home. Foster caregiving and functional proxy relationships in neighbourhoods are accepted practices in some of these programs<sup>16</sup> to protect the right to live in place of choice and not be forced to live in isolation and segregation from natural communities. The programs also multiply emotional effects by plugging into and capacity building existing Local Actor Networks, for example, the education system, local healers, health workers, development workers, traditional healers, etc. While these social relationships may have their stresses and strains, and negotiations mediated by the service providers and other community members, we offer that they are devoid of the legal normative power of penal admission, institutionalization or guardianship.

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<sup>15</sup> Seher program of the Bapu Trust for Research on Mind and Discourse, Pune, India.  
<https://www.youtube.com/watch?v=t5PC0yBK3ow> accessed on 25-02-2016

<sup>16</sup> Shared in TCI Asia consultation on Legal capacity, Incheon, Korea, 18-19 November 2015, Orakai Sangdo Hotel, Incheon.